



**World Network of Users and Survivors of Psychiatry (WNUSP)
Submission for OHCHR Thematic Study on Political Participation
October 15, 2011**

The right to political participation encompasses two main features: the right to vote and stand for election, and the right to have an effective means of influencing political decisions pertaining to oneself and one's own community. These elements correspond to paragraphs (a) and (b) of Article 29, in which States Parties undertake:

- (a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected
- (b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
 - (i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
 - (ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

The right to political participation is concerned with self-representation at the public level, and as such is related to legal capacity (Article 12) as well as to the obligation to closely consult with organizations of persons with disabilities on matters pertaining to themselves (Article 4.3). The obligation to promote an environment to conducive to participation in public affairs also entails awareness-raising activities (Article 8).

The right of people experiencing discrimination to participate in decisions affecting themselves is a fundamental right in itself and not

only a means to an end (OHCHR Principles and Guidelines on a Human Rights Approach to Poverty Reduction Strategies, HR/PUB/06/12; Human Rights Approach to Poverty Reduction: A Conceptual Framework, HR/PUB/04/1). The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities affirms that influence in decision-making bodies is necessary to fulfill the right to participation; participation is not mere presence in a room but has to be conducive to producing results (A/RES/48/96, Rule 17).

The right to political participation by people with disabilities applies in states that have not ratified the CRPD, by virtue of their obligation to guarantee to persons with disabilities all rights recognized in the Universal Declaration of Human Rights, including the right to take part in the government of one's country, and universal and equal suffrage (UDHR Article 21; see also ICCPR Articles 2, 25 and 26).

I. Legal capacity and the right to vote

A. No distinction or priority among aspects of legal capacity

For users and survivors of psychiatry, it must be said that the right to vote is of no greater importance than other rights in the exercise of legal capacity, and that the right to legal capacity *in all aspects of life* is of immediate application. Other aspects of legal capacity, such as the right to control one's own health care and to defend one's own physical and mental integrity (Articles 15, 17 and 25), the right to decide where and with whom to live and to not be placed in an institution against one's will (Articles 14 and 19), and the right to control one's own finances (Article 12.5) are of more pressing significance in individuals' lives than the right to vote. While the right to vote is an important right, the aspects of legal capacity that are more closely related to personal survival are of equal or greater importance for WNUSP's membership.

For that reason, WNUSP is uncomfortable with advocacy strategies that place a strategic importance on securing the right to vote for people who are placed under plenary guardianship. The CRPD requires abolition of all forms of guardianship, both plenary and partial, and requires as an immediate obligation the removal of barriers and restrictions to the full and equal enjoyment of legal capacity in all aspects of life by all persons with disabilities. The right to vote cannot be singled out for preferential enforcement while people are still suffering under guardianship regimes, institutionalization and compulsory treatment amounting not only to torture but also to forms of modern slavery.

B. Competency standards cannot be imposed on the right to vote

1. Competency standards violate Article 12

Equal enjoyment of legal capacity is emptied of content if incompetency can be adjudicated in an individualized determination, with respect to an area of life (as in a limited guardianship proceeding) or with respect to a particular decision.

Tests of competency either contain a threshold criterion of disability (such as the UK Mental Capacity Act) or implicitly apply only to persons whom others believe fail to comprehend the nature and consequences of an act due to a disability rather than due to ignorance or inexperience. Competency evaluations can never be CRPD-compliant as they result in deprivation of legal capacity based on disability for some subgroup of persons with disabilities.

WNUSP members have consistently rejected any limitation on the right to make decisions, and also affirm the principle of equal responsibility.¹ In our experience, the potential gains of avoiding responsibility are vastly outweighed by the traumatizing effect of being deprived of autonomy and control, the limiting effects of diminished opportunities, the inability to defend ourselves from violence (including forced psychiatric interventions) at the hands of those appointed to make decisions for us, and our actual experience that others do not make better decisions for us than we make for ourselves. Many of us have already survived extremely difficult circumstances such as prison, homelessness, rape and other forms of violence, and psychiatric institutionalization. We do not believe that removing our right to make decisions for ourselves will protect us, and we are willing to take our own risks. We believe in creating genuine human relationships that are capable of supporting each other and being mutually responsible to each other even when our personal comfort is challenged.²

2. Competency standards violating the right to political participation in Europe and United States

¹ WNUSP Submission to October 2002 ESCAP Meeting on Disability Convention, WNUSP Advocacy Note on Legal Capacity, WNUSP Kampala Declaration on the CRPD, WNUSP Statement on CRPD and Forced Treatment, WNUSP Submission to CRPD Committee for Article 12 General Comment, available at www.wnusp.net or from humanrightsinfo@wnusp.net on request.

² This formulation owes a great deal to the work of Shery Mead, www.mentalhealthpeers.com.

Deprivation of the right to vote based on an individualized determination of competency with respect to voting violates CRPD Articles 5, 12 and 29.

Contrary to CRPD obligations, the Venice Commission's Council for Democratic Elections, as an alternative to its original interpretive declaration stating that the right to vote can be deprived based on "proven mental disability." The revised version would read:

Universal suffrage is a fundamental principle of the European Electoral Heritage. People with disabilities may not be discriminated against in this regard. Nevertheless, a court, in an individual decision, may consider that the lack of proper judgment of a disabled person may prevent him or her from exercising his or her right to vote or to stand for elections.

The European Court of Human Rights left the question open in *Kiss v. Hungary* (Application No. 38832/06, decided 20 May 2010), concluding that:

An indiscriminate removal of voting rights, without an individualised judicial evaluation and solely based on a mental disability necessitating partial guardianship, cannot be considered compatible with the legitimate grounds for restricting the right to vote.

United States law takes a similar position. In 2001 a federal court struck down Maine's constitutional provision depriving people of the right to vote if they were under guardianship and were diagnosed with a mental illness, as incompatible with the federal constitution and the Americans with Disabilities Act, *Doe v. Rowe*, 156 F.Supp.2d 35 (D. Me. 2001). However, the decision assumes that the right to vote can be deprived based on an individual finding of incompetency to vote as part of a guardianship proceeding. The United States is a signatory to the CRPD but has not yet ratified.

C. Recommendations:

- Any and all declarations on the rights of persons with disabilities to vote and to stand for election must be contextualized by reaffirming the immediate obligation to recognize the equal right of persons with disabilities to enjoy legal capacity in all aspects of life, without exception.

- The right of persons with disabilities to vote and to be elected must be recognized, respected and fulfilled on a basis of both formal and substantive equality and non-discrimination, and not subjected to the conditionality of competency, which impacts disproportionately if not exclusively on persons with disabilities. Similar reasoning applies to the deprivation of legal capacity in any aspect of life, and to the deprivation of any other human rights.

II. The right to political participation in context

A. Advocacy in Rwanda

Electoral Commission Order No. 003/2011 of 12/02/2011, regarding the special group's elections, (women, youths and people with disabilities) Article 14, lists down the persons whose rights to vote were deprived of by the courts of law due to crimes they committed, and "persons with mental disability" appears on the same list. This violates Persons with disabilities' civil rights: because even though they are actively contributing to the country's economy, they are unable to participate fully in the country's political process. *Both The constitution of Rwanda and the UNCRPD (United Nations Convention on the rights of persons with Disabilities) prohibits discrimination based on disability. (art 2 of the Constitution of Rwanda and 12 of the CRPD³)*

from Fact Sheet NOUSPR/FOSI No. 001-12/05/2011
Reporting the State of Persons with Psychosocial Disabilities in
Rwanda 2011
National organization of users and survivors of psychiatry in
Rwanda
(NOUSPR-Ubumuntu)

According to NOUSPR leader Sam Badege, national law prohibits people with psychosocial disabilities from standing for election, and there have been reports of local electoral officials using this law to even prevent those labeled as "mad" from voting. NOUSPR has embarked on an awareness-raising campaign including monitoring of elections. Of particular concern are the elections for committees of representatives of persons with disabilities, from cell level to sector level, district level, provincial level and then to the national level.

In the same fact sheet, members of NOUSPR speak out about their experience of human rights violations:

³ Rwanda is a signatory to the CRPD but has not yet ratified.

IN THEIR OWN WORDS:

"Our human rights are at the stake! In so many forms we have been discriminated against, our relatives have expressed that they don't want to live with us and we are chased from our houses. Landlords, when they hear or are convinced that we have ever experienced mental health challenges, just chase us out without an eviction notice" **Seminega.**

"People say they don't want to give us food for free. Employers won't pay us when we work for them. When we are employed, our workmates tease us. At work we have no right to information...; they call us names - all the derogatory words you can think of. The community simply forget or ignore us when they detect we are suffering from this kind of disability. When we try to resist this kind of treatment, we are suppressed because "we are the mentally disturbed"; and with the use of this label, they justify their fear and avoidance of us." **Rose**

"Many people are not well informed about psychosocial problems, and they often misinterpret us. Their listening skills need to be improved, they make quick and often wrong conclusions about our situation" **Batiste.**

"We are sentenced then we are feared. We are sometimes subjected to excessive pity and the belief that our lives are sad and have little value. We are often told we will never get better. We know that if we talk about our experience of mental illness or distress, we lose our friends; we lose a place and status; we are denied all the services we are entitled to as human beings...." **Geovan.**

We live in police cells; we live on streets; we eat from garbage; we roam around the places seeking food.... We commit suicide because we are tired of life; we die of hunger because we are denied food; we die on streets because we cannot get medicine; we are dirty because we are denied access to water; we are isolated because we cannot be heard...." **Kalekezi.**

"Many people in medical service still assume they know what services we need and how to provide those "good services" to us without even seeking our consent. We are the ones using the services they give to us but we have no power to change them; we can't even go to other services. Many mental health services continue to treat us without respect, equality and protection of our rights - especially our right to informed consent is suppressed." **Venuste.**

The NOUSPR advocacy project aims at raising awareness at a basic level of the citizenship and personhood rights of people with

psychosocial disabilities. It illustrates the interdependence between political participation and other human rights. By mobilizing for the right to participate in elections and speaking out about human rights violations, users and survivors of psychiatry hope to interrupt the cycle of discrimination, placing their rights on the national agenda.

B. Advocacy in Uganda

A lady member of parliament (MP) who had a psychosocial disability but not yet empowered to openly declare used to go for psychiatric services in as an out patient from Butabika Hospital the National referral Mental Hospital. She was seen by fellow MPs. Due to her active participation and political affiliation to the ruling party (NRM); she was nominated by cabinet to become a minister.

The vetting done in parliament used some of the simple discriminatory legislations which hinder a person with a psychosocial disability to take up any public office and indeed she lost the chance to serve her nation as a minister. We have MPs representing persons with disabilities in parliament; deaf, blind and three with physical disabilities. None of them stood to defend our rights or even remind the legislature about the CRPD which Uganda signed and ratified.

The recent election of parliamentary representatives for PWDs; we were not invited to exercise our inherent rights as enshrined in article 12 and 29 of the CRPD. We however, gate crashed the election venue with placards protesting against exclusion. This attracted the attention of election observers from the European Union and they gave us an appointment to hear from us at Mental Health Uganda secretariat. We have written a strong memorandum to the Chairman Electoral Commission and copied to the Human Rights Commission about such evident exclusion which violate the CRPD and the Ugandan Disability Act.

In the disability umbrella organization (NUDIPU) in a workshop to domesticate the CRPD still negative discriminatory statements were made by fellow PWDs. That some people have joined the disability movement because there is money yet they are not persons with a disability. I had to read for them the preamble of the CRPD noting that persons can be disabled by attitudes and that is where persons with Psychosocial disabilities fall. We educated them that we are also PWDs and well enshrined in the CRPD.

- contributed by Daniel Iga Mwesiga, WNUSP board member, Uganda

Daniel Iga Mwesigwa also reports that he has been named to a committee reviewing the Mental Health Act but in fact he is not informed of meetings and decisions are taken without his participation. He says:

The truth is mental legislation is drafted and made by Psychiatrists and their allied professionals. It actually legalises them to abuse our rights under the guise of best interest of the patient. In my analysis it is to their best interest to silence us using strong tranquilizers and using seclusion rooms as a mode of punishment as opposed to treatment.

Uganda is in the process of drafting a mental health bill and repealing the old one. I was nominated to be on the drafting bill. I was very surprised when I just learnt that the draft bill is at the ministers table waiting to be presented in parliament. The final meeting was held in Butabika National Mental Hospital. I had to gate crash uninvited and we had a serious heated argument as to why they developed a bill which is based on MI principles [Principles for the Protection of Persons with Mental Illness, a non-binding declaration that contravenes the CRPD by accepting involuntary treatment and involuntary confinement, see Special Rapporteur on Torture A/63/175 paragraph 44] yet Uganda signed and ratified the UNCRPD. Also why users/survivors were not involved fully from the beginning to the end and use of my name to legalize user involvement. The Consultant forensic Psychiatrist just rubbished my trend of thinking. He arrogantly talked about a national situation analysis which was made as a users involvement (Medical model of approach).

With the help of Basic needs we drafted our memorandum and took it to parliament. We hope the social committee will call us to substantiate our concerns. I also talked about the social support which is cut off from a mental patient as a violation of the freedom to associate which impact negatively to the healing of the patient. They could not substantiate it but alleged that we are danger to non skilled people; but yet before coming to hospital this patient harmed no body. There was a contradiction between them because Mulago National Referral Hospital's Mental ward allows attendants and they have proved that the healing is faster.

My question now is with these institutions still working in our

countries without a legislation how shall we hold them accountable as duty bearers and us as rights holders?

These reports from a WNUSP board member disclose several violations of the right to political participation:

- Legislation that discriminates against people with psychosocial disabilities was used to prevent a qualified MP from serving her country as a minister.
- People with psychosocial disabilities were excluded from an election to represent persons with disabilities in parliament, under Uganda's system of constituency-based representation. This exclusion discriminates against people with psychosocial disabilities both in their right to vote in an election for which they should be eligible voters, and by undermining their participation in public affairs as part of the disability community.
- Both governmental and non-governmental representatives of the disability movement lack awareness of people with psychosocial disabilities as being part of their community and having rights under the CRPD. This undoubtedly limits the ability of people with psychosocial disabilities to influence and effectively participate within disability umbrella bodies.
- Decisions are being taken on legislation adversely affecting the rights of users and survivors of psychiatry, without the close consultation required by CRPD Article 4.3 and in a process that disrespects their leadership and undermines their ability to effectively influence the outcome.

People with psychosocial disabilities in Uganda, and their organization Mental Health Uganda, continue to advocate for their rights to political participation and for full compliance with the CRPD.

C. Additional Issues and Recommendations

- People with psychosocial disabilities must be guaranteed the right to vote and not excluded from voter eligibility on the basis of their disability or on the basis of their competency as perceived by others.
- Psychosocial disability must not constitute a disqualification for any public office.
- People with psychosocial disabilities must have the right and opportunity to participate in electing representatives of the disability community in governmental bodies, including parliament and disability councils at every level of government,

and the right and opportunity to stand as candidates in such elections.

- Government policy with respect to disability umbrella federations, including official recognition and distribution of resources, should require the inclusion of organizations of people with psychosocial disabilities wherever such organizations exist, and support for the establishment of such organizations if they do not exist. Family organizations and service provider organizations do not meet this requirement.⁴ WNUSP defines a user or survivor of psychiatry organization as “an organization run entirely by users or survivors, or where the majority of members and people in a governance role are users or survivors.”⁵
- Organizations of people with psychosocial disabilities often have little or no financial resources, in countries at all income levels. Governments and intergovernmental organizations should ensure that their own funding policies and criteria do not weaken the ability of user/survivor organizations to effectively represent ourselves and influence public affairs, and should explore with our organizations what is needed to enhance our participation. Non-governmental funders should be encouraged, and required where possible, to do likewise, and should adopt policies of adherence to CRPD principles in their own practices.
- Governmental and inter-governmental funding should be given to user/survivor organizations without compromising their independence or limiting their advocacy, and should not be channeled exclusively through mental health, health or social welfare ministries.⁶ Non-governmental funders should be
- People with psychosocial disabilities must have meaningful and effective opportunities to influence the drafting of legislation concerning their rights, and to ensure that any such legislation complies with the CRPD. In reviewing mental health and

⁴ In Denmark, the only national user/survivor organization LAP has not been admitted to the disability federation due to the presence there of a traditional mental health association organizing counting relatives, service providers and some users amongst its members.

⁵ WNUSP Statutes, Article 3.2, available at www.wnusp.net.

⁶ The user/survivor movement in the United States has both benefited and suffered from funding through mental health agencies. This funding has allowed the movement to grow in numbers and develop peer-run agencies and projects, but it has also limited advocacy. The federal mental health agency SAMHSA, which funds an annual Alternatives conference, does not allow the conference to have workshops on organizing and vets the speakers and annual theme.

capacity legislation, governments should bear in mind that the CRPD prohibits legislative provisions that authorize involuntary confinement or involuntary treatment of people with psychosocial disabilities, or that authorize the removal of legal capacity or the right to make decisions from persons with psychosocial disabilities.⁷

- Complementarity and inter-relatedness of political participation with other civil, political, economic, social and cultural rights must be addressed. Discrimination in any aspect of the right to political participation reflects and reinforces a larger pattern of discrimination in law and in society.

⁷ CRPD Articles 5, 12, 14, 15, 17, 19 and 25; CRPD Concluding Observations on the Report of Tunisia, CRPD/C/TUN/CO/1, paragraphs 24-25 ; OHCHR Thematic Study on Legal Measures, A/HRC/10/48, paragraphs 43-48; Report of the Special Rapporteur on Torture, A/63/175, paragraphs 44, 50, 72 and 73.

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The World Network of Users and Survivors of Psychiatry is a democratic organization of users and survivors of psychiatry that represents this constituency at the global level. In our Statutes, "users and survivors of psychiatry" are self-defined as people who have experienced madness and/or mental health problems, or who have used or survived mental health services.

WNUSP had its beginnings in 1991 and became a full-fledged organization with a democratic global structure on adopting its statutes in 2001. Currently we have members in over 50 countries, spanning every region of the world.

WNUSP is a member of the International Disability Alliance (IDA), and is represented on the Panel of Experts of the UN Special Rapporteur on Disability.

WNUSP was involved in the work on the Convention on the Rights of Persons with Disabilities (CRPD) since the inter-regional expert meeting convened by the Mexican government before the 1st session of the Ad Hoc Committee (the UN forum in which the CRPD was negotiated), and has been active and successful in achieving our aims for the Convention, especially with regard to legal capacity, liberty, integrity and free and informed consent, as well as principles of autonomy, human diversity and equality reflected not only in article 3 but throughout the Convention. WNUSP brought over 20 users and survivors of psychiatry to the UN, from every region of the world, in addition to representatives of other user/survivor organizations that worked closely with us, such as Mind Freedom International and People Who.

WNUSP was among the organizations that created the International Disability Caucus, and served on its steering committee; it is also currently on the steering committee of the IDA CRPD Forum. WNUSP was also one of the organizations represented in the 2004 working group that produced the first official draft text of the CRPD, and was represented as one of two civil society speakers at the adoption of the CRPD by the General Assembly.

Since the adoption of the CRPD, WNUSP has produced an Implementation Manual from a user/survivor perspective (available on our website), and continues to work with the rest of the international disability community, especially through the Legal Capacity Task Force, a working group of the IDA CRPD Forum.

WNUSP has Special Consultative Status with the Economic and Social Council of the United Nations (ECOSOC).

Please see our website www.wnusp.net for more information.